special attention was paid to contextual and environmental factors. The final grid (G-MAP) was administered to 15 subjects with traumatic brain injury (TBI group) and 15 subjects with schizophrenia (TS group). Assessments of cognition, neurobehaviour, psychological and psychosocial functioning were also performed.

Results.– The G-MAP is a 26 items tool related to 6 ICF sections, providing ordinal rating of activity limitations, participation restriction and contextual factors (social support, attitudes, systems and politics) for each item. The internal consistancy of activity limitations (alpha = 0.89) and of participation restriction (alpha = 0.89) is satisfying. We observed no difference on psychological variables between the two groups, except for a lower social support in TS group. Results of G-MAP underline that the two groups are confronted with the same activity limitations in personal care, leisure and community life (non significant U of Mann-Whitney). However TS group seems to be more limited than TBI group in interpersonal relationships, economic and social productivity and domestic life. TS group is also more concerned by participation restriction than TBI group, except for community life. Conclusion.– The G-MAP is a useful, feasible and relevant tool for assessment of psych or cognitive disability. It allows assessing in a detailed and individualized way participation restriction of a patient in his environment.


CO36-007–EN

Patient reported outcome in neuromuscular diseases: The QoL-NMD. Qualitative and quantitative generation of items


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Keywords: Questionnaire; Quality of life; Muscular diseases; Psychometric; Focus group; Delphi

Introduction.– There are very few tools capturing subjective perceptions of people with specific motor neuromuscular diseases. The theoretical approach used for the construction of QoL-NMD tool based on the gap between the aspirations of the subject and resources. Experiences of this gap are defined as a qualitative measure known as health related quality of life or subjective patient reported outcome.

Materials and methods.– A multidisciplinary committee of experts (physiotherapists, psychologists, neuropsychologists, methodologists, biostatisticians, linguists, patients) was formed. It established the specification charges, reached consensus on major decisions such as domain choices, generation of items, the metric used. Patients were suffering from slow progressive neuromuscular disease. Five focus groups were made in four French centers (Angers-Nantes, Créteil, Lille, Reims). Each verbatim from these focus groups was then analyzed in terms of frequency of the CIF approached by patients. Items were constructed in relation with these ideas according to the methodology QAS99 and were reduced by Delphi iterative methods among experts. Finally, the bank of items was tested to verify its feasibility and face validity.

Results.– Forty-one individuals were included in the focus groups. Verbatims were processed in 333 initial items grouped into 5 domains: physical symptoms impact, self-perception and projection into the future, satisfaction of environment and accessibility of care, activities and participation, optional respiratory module. After Delphi methodology, number of items was reduced to 114 items. Fifty-six multicenter patients, kindly filled the item bank. The average duration was 32 ± 14 minutes. The acceptability, understanding and level of item responses were analyzed and modified if necessary.

Discussion.– The final item bank is made feasible, accepted by patients with neuromuscular diseases. A second stage, structure validity and the metric of the tool is in progress.


CO36-008–EN

HADS scale in adults suffering from Steinert myotonia: Reproducibility and internal consistency


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Keywords: Questionnaire; Reproducibility; Internal consistency; Depression; Muscular diseases; Dystrophy myotonia

Introduction.– Screening for anxiety and depression is likely to be overestimated in patients with physical disabilities such as Steinert dystrophy patients. This overestimation results from the high weight of scores for items assessing motor adynamia and in the other hand, the characteristic anemic face these patients present. Hospital Anxiety Depression Scale (HADS) has the advantage of not inquiring items on motor skills. This work seeks to verify the reliability of the anxiety and depression HADS subscales and their reproducibilities in patients with Steinert myotonia.

Materials and methods.– Thirty-five patients suffering from Steinert myotonia (11 men, 24 women) responded twice to the HADS questionnaire. The delay between the two HADS evaluation was on average 18 ± 12 days. It was verified by examination that no health problem had occurred between test and retest of the questionnaire HADS. The HADS is a self-administered questionnaire comprising 14 items, 7 items measuring the depression likelihood, 7 other items assessing the anxiety risk. The reliability of two subscales was checked by calculating Cronbach alpha coefficients and test-retest reproducibility of the scores by intraclass correlation coefficients (ICC).

Results.– For the subscale ‘anxiety’ test and retest scores were respectively 7.94 ± 3.68 (11 men, 24 women) versus 7.94 ± 3.89 (12 men, 23 women). The ICC was 0.77. Six patients had a score ≥ 7.14 relating a pathological anxiety (17%).

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